

JOINT MEETING OF

IDEA/ICC

Thurs, June 4, 2009

Doublewood Inn, Bismarck

**MEMBERS PRESENT**

*IDEA Members*

Rita Weisz

Lisa Bjergaard

Debra Huber

Carol Jabs

Edna Keller

*NDICC Members*

Tammy Gallup-Millner

Linda Jagielo

Scot Hoeper

Arlene de la Paz

Holly Major

Shawnda Ereth

Bob Rutten

Jill Staudinger

Deb Balsdon

Laura Larson

Sen. Dick Dever

*Staff*

Colette Perkins

Roxane Romanick

Kathy Smith

*Guests*

Donene Feist

Missi Baranko

Tanisha Baranko

Kathy Barchenger

Introductions were made.

**TOPIC: FAMILY STORY – Donene Feist, Family Voices of ND**

Donene is the Executive Director of Family Voices of North Dakota. Donene was recently named a recipient of the Robert Wood Johnson Community Leaders award. She shared the story of learning of her children's diagnosis, trying to figure out a service delivery package that worked for her family, and her efforts in learning to navigate the service delivery system. Donene shared some of the professional recommendations that were made for them as a family, such as traveling to Fargo for speech therapy three times a week, and what type of impact that had on them emotionally and financially. She shared that she first became involved in leadership activities when she was asked to be part of the Family Involvement Subcommittee for the NDICC. This led her to work actively on a family to family matching program for the state of North Dakota. It was through this effort that she first met founding members of the national Family Voices organization and went on to establish a chapter office here in North Dakota. She noted that she now challenges other parents of children with special health care needs to get involved in leadership activities to work towards improving the system of care. The video that was prepared by Robert Wood Johnson on Donene can be found at:

<http://www.rwjf.org/newsroom/product.jsp?id=36028#content>

**TOPIC: SEPTEMBER & DECEMBER MEETING MINUTES REVIEW**

**ACTION:**

- A motion was made by Holly Major and seconded by Senator Dever to accept the September minutes as distributed. Motion carried.
- December minutes – Corrections were noted on the 3<sup>rd</sup> pg in spelling of Brenda Oas' name. In addition, Roxane noted that staff did not get the name of the individual that seconded the motion regarding going to 2 meetings per year between IDEA and NDICC. No one could recall from available membership – this was left blank. A motion was made by Laura Larson to approve the December minutes as corrected and seconded by Senator Dever. Motion carried.

**TOPIC: OVERVIEW OF AGENDA**

**ACTION:**

- Tammy reviewed the agenda with members.
- Other items: group to work on inclusion in child care and have some discussion.

**TOPIC: MEMBER UPDATES AND ISSUES**

## **ACTION:**

- Laura Larson provided an update on changes to the federal COBRA laws. There is now a federal subsidy to offset the cost of COBRA premiums. This will benefit families struggling with the costs of health insurance especially with COBRA. You can contact the insurance department or Laura to get more information. Another resource is the federal labor department website. The subsidy can assist with 65% of the payment.
- Laura also updated the committees on Chat which is coming through the senior health insurance counseling. Doing survey on how North Dakotans make decisions about health insurance needs. Looking for anyone to participate, to get a better idea of how people make the decisions they make about their health insurance. For information:  
<http://www.nd.gov/ndins/uploads%5Cresources%5C518%5Cchatinfosheet.pdf> or to register for CHAT: <http://www.nd.gov/ndins/about/chat/>
- Roxane reported that the Grand Forks Buddy Walk for Down syndrome awareness is July 30 and Bismarck's Buddy Walk is scheduled for Saturday, Sept. 26th.
- Donene Feist noted that through her involvement with national policy advisory for Family Voices, it appears that there will be a health care reform bill in the next 2 weeks. Federally, this is moving faster than everyone thought it would.

## **TOPIC: LEGISLATIVE UPDATE**

### **ACTION:**

Deb Balsdon reported on the following pieces of legislation:

- SB 2423 – DHS shall conduct reviews of audit and reimbursement process as well as conduct a review and reconsideration of the 95% occupancy rule.
- HB 1012 – DHS budget – The DHS budget included a dollar per hour increase except for administrative positions in DD providers (including Infant Development), and an inflationary increase of 6% of each year of the biennium; included funding for intense medical needs for adults which will assist with individuals aging in their current residences while continuing to meet their medical needs; included funds that are targeted for individual being cared for in family homes that have intense medical needs; additional funds for enhancements for those with severe medically fragile or behavior challenged needs who are residing outside of their parental home with a provider; funding was added to establish a CARES team out of the Developmental Center which will allow for additional behavior analysts to keep individuals with developmental disabilities in the community. Individuals do have to be eligible for DD Program Management services. Deb added that the budget bill includes language that says DHS can borrow up to \$8.5million if the budget that was set was under-estimated during this session.
- HB 1516 – provides another study by DHS of rates of public and private licensed DD providers who serve individuals with intense medical and behavioral needs. This study includes an appropriation of \$200,000.

Bob Rutten reported on the following legislation:

- Bob distributed a brochure relating to recruitment strategies for special education and speech pathology. This recruitment effort is aimed at middle and high school students who are just determining a career path. This is work that came out of the personnel development grant.

- Bob shared with the group a listing of pertinent legislation. He noted that a seven page document was just prepared for DPI on the bills that were considered and passed this session.
- HB 1078 – Acquisition of instructional materials in alternate formats. This was a bill that was sponsored by DPI. This legislation allows children with disabilities to be able to receive accessible instructional materials at the same time as non-disabled peers. The legislation gives the ND Vision Services a broader mission to serve kids with other disabilities other than those with just vision concerns.
- SB 2155 – authorizes funding for the ND university system to provide interpreters and real time captioning services for ND students attending ND colleges. Bob remarked on the impact of one individual that testified at the hearing, utilized the services of an interpreter, and talked about his college plans to attend BSC, including the need for interpreter services.
- HB 1013 – This bill addresses the future plan and implementation for the ND School for the Deaf. It was noted that service needs are changing for children who are hearing impaired. At one of it's peaks, the School for the Deaf had 135 children that resided and attended school there. Enrollment now is currently in the low 20's. This legislation directs the department to put a transition team together by July 1<sup>st</sup> to address service delivery needs of students that are still residing there. Questions were asked whether or not there is anything in the bill that will affect the Parent-Infant Toddler staff that work in the field. Bob responded that it probably would to the extent that services may be expanded. He noted that the current hearing impaired population according to IDEA categories is about 109 children. Another question was asked about the status of the ND School for the Blind. Bob noted that the School for the Blind went through restructuring several years back and now also has a large expansion of outreach services to the adult population.

Linda Jagielo reported on the following legislation:

- SB 2162 – This legislation modified century code for early childhood and child care. Gov and leg change the way of doing background checks. This includes the language for mandating background checks.
- HB 1472 – Created an Early Childhood Services Advisory Board for advising on the creation of child care rules. This legislation passed and currently needs to be established. The legislation requires a seven member board and geographical representation.
- HB 1418 – The language in this bill works toward developing quality in child care settings through professional development, upgrades, and technical assistance. All but the quality rating improvement scale language remained intact, but the appropriation was pulled from the bill. ARRA funds of \$3.6 million were attached however the department continues to try to match up federal and state requirements to make this work.
- SB 2225 – This bill awarded the Department of Commerce \$1.75 million for grants to child care entities. These funds can also be used for quality improvement.
- SB 2161 – removing code from state broadcasting under the responsibility of the Attorney General's office with the Bureau of Criminal Investigations. The language notes that all child care providers need to verify the identity of children within 45 days of enrollment.
- Linda reported that she recently held a public comment hearing for the child care development block grant. It noted during this hearing that we continue to need health care consultants to address children with special health care needs. They will continue to consider this need as they outline the block grant and consider the possibilities under HB 1418. A question was asked whether

or not any of the pieces of child care legislation directly impact children with special health care needs. It was noted that all quality improvement work should benefit children with special health care needs. Donene Feist reported that Region VI RICC is planning on having a Child Care Summit in the fall of 2009.

- HB 1400 – This bill contains language for the establishment of an early learning council. The language was meant to mirror the federal language in the Head start reauthorization bill. At this time, no one has been appointed to this council but the language does lay out who will be represented on this. Bob noted at this time that one of the recommended uses for IDEA Part B ARRA funds is the expansion of the availability and range of inclusive placement options for preschoolers with disabilities by developing the capacity of public and private preschool programs to serve all children. There is also activity around use of Title I dollars for preschool development. There was discussion about how DHS/DPI/DOH need to continue to work together in the area of early childhood to make sure that we have a coordinated effort that ensures the health and safety of children.

Tammy Gallup-Milner reported on the following legislation:

- Early hearing detection and intervention (EHDI) - The Department of Health received about \$50,000 in additional funding through the legislative process to assist with this process. One suggestion that is being considered for the use of the funding is to include primary care physicians as a support to encourage the follow-up on hearing screenings. This included including the hearing screening on the immunization schedule. **The department is open to other suggestions. Contact Tammy at [tgallupmilner@nd.gov](mailto:tgallupmilner@nd.gov) with further suggestions.** A suggestion was made to make sure that families whose children are failing the screenings are hooked up and have access to family support agencies.

## **TOPIC: REPORT ON PATHFINDER'S SPRING CONFERENCE**

### **ACTION:**

Holly Major, interim director at Pathfinder Parent Center presented a powerpoint with the following information:

- 188 attendees.
- Had plenary and breakout sessions.
- Had 25 different concurrent sessions.
- 90% of people completed the survey.
- The two largest groups attending were parents and special education teachers.
- They are considering having Dave Anderson, from famous Dave's, to present next year as well as Dan Habib, producer of Including Samuel.
- The conference is scheduled for May 6, 7, & 8, 2010 at the International Inn in Minot. The conference will be in Bismarck in 2011.
- **If you have suggestions for next year's conference, contact Holly at this address - [familysupport@srt.com](mailto:familysupport@srt.com).**

- Roxane reported that one of this year's presenters, Jennifer Graf Groneberg, has an article in this month's Exceptional Parent magazine.

**TOPIC: STATUS OF ND AUTISM PROJECTS: Autism Task Force,**

**Autism Waiver, Autism State Plan**

**ACTION:** Additional legislation that was reported on:

- SB 2174 – This legislation directs the Department of Human Services to establish an autism task force to create an autism state plan by July 1, 2010. Presently, the department is taking names for the task force. Interested persons need to contact Vicki Magill by 6-11-09. Deb Balsdon noted that currently the task force does not specifically include a speech therapist – they would like to recruit a speech therapist that would fulfill another position on the task force. The list includes the following positions:
  - Pediatrician with expertise in the area of ASD
  - Psychologist with expertise in the area of ASD
  - College of Education faculty member with expertise in the area of ASD
  - Licensed Teacher with expertise in the area of ASD
  - Occupational Therapist
  - Representative from a health care insurance operating in this state.
  - Representative from a residential treatment center for children with ASD
  - Parent of a child with ASD
  - Family member of an adult with ASD
  - Member of the legislative assembly
- The task force is required to meet quarterly and has several areas to study: 1) early intervention and family support service – supports available in communities in North Dakota; 2) transitional programs and supports that assist individuals transitioning from school based to adult day program; 3) examine workforce needs and development; 4) explore potential costs; 5) explore federal resources directed to the provision of these services.
- The task force is required to create an annual report of the state plan for the governor and legislative council.
- Deb also reported on the status of the Autism Waiver. The funding for this waiver was approved through the DHS budget process. The waiver is to be implemented by 7-1-10 but is contingent on the activation of the MMIS system. Thirty slots were funded. The age range continues to be birth through 5 year of age. The waiver would also establish an "expert team" that would assist with identification and strategy implementation. This waiver may also include Infant Development services. Individuals must be Medicaid eligible and meet the ICF/MR level of care as well as have a diagnosis on the spectrum.

- Deb noted there is a discussion about using funding from American Recovery and Reinvestment Act to additional training set up. Consideration of Pivotal Response training.
- Bob Rutten talked about providing some additional training for professionals working with students with autism. Bob distributed a document on “Autism Spectrum Disorders in North Dakota Public Schools.” Information was shared by some of the committee members on a software product called Autism Pro. This allows IEP and other planning teams to create options and have access to resources that will manage data while engaging in specialized instruction with a child.
- Tammy Gallup-Milner reported that Children Special Health Care Services is in the process of supporting an autism clinic in two locations in ND. This in response to a request from the medical community to fill the gap on diagnosis.
- Deb noted that a ND team attended the Act Early/Learn the Signs conference sponsored by the CDC earlier this spring. This group is looking at ensuring that young children have access to developmental screenings.
- Tammy shared the results from National Survey of Children’s Health and noted that only 17.6% of ND children, ages 10 months to 5 years received a standardized screening for developmental or behavioral concerns. The national percentage was 19.5 %. The complete survey results can be found at: <http://www.nschdata.org/Rankings/StateRankings.aspx>

#### **TOPIC: INCLUSION IN CHILD CARE**

##### **ACTION:**

- Linda Jagielo asked the joint committees to discuss the development of a subcommittee to create a document relating to inclusive child care for child care providers. Linda presented a document from Wisconsin that she would like to see duplicated in ND: <http://www.disabilityrightswi.org/wp-content/uploads/2008/02/thinking-guide-to-inclusive-child-care.pdf>
- Suggested membership included: One person from the IDEA committee, one from ICC, childcare licensing, children resource and referral consultants, early intervention, infant development, ECSC, child care provider that cares for someone with special needs.
- A question was raised about who would supply the funding for this project/materials/etc – Linda noted that she would find the necessary funding.
- Holly Major volunteered to help.
- A suggestion was made to put together a proposal for funding through the DD Council.
- No formal motion was made to move forward; however there was interest generated with the members that remained at the meeting during this time.

#### **TOPIC: NEXT MEETING**

##### **ACTION:**

- Next meeting is September 10.
- IDEA - more interest in webinar meetings and develop more formal agendas – survey members on what they want/need. A decision was made for the Executive Committees to meet to decide on agenda for September meeting.